A background image showing a hand holding a yellow envelope, with several white envelopes scattered around it. The image is dark and moody, with the text overlaid in white.

Using evidence for advocacy impact

ZACK PEMBERTON-WHITELEY

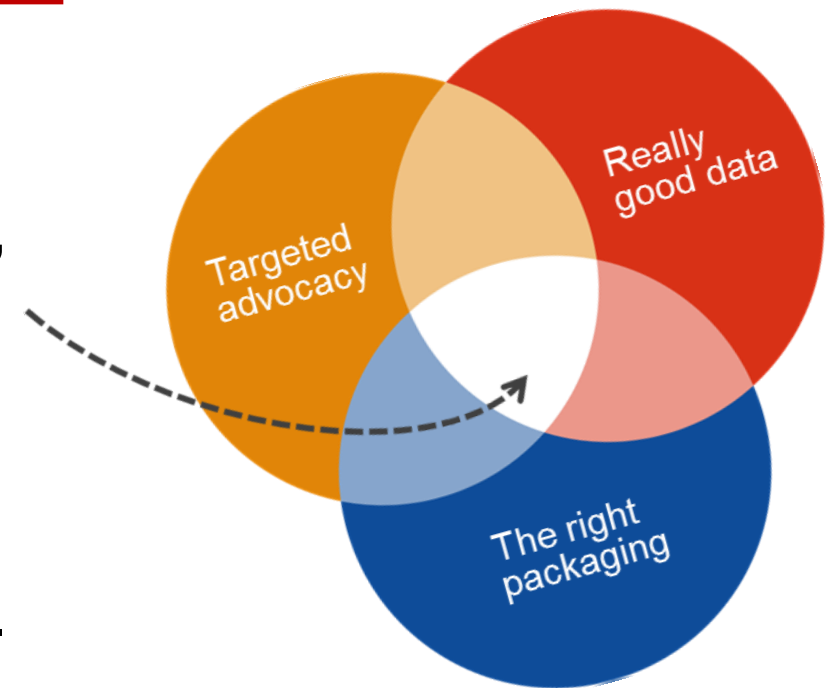
LEUKAEMIA CARE – CHIEF EXECUTIVE OFFICER

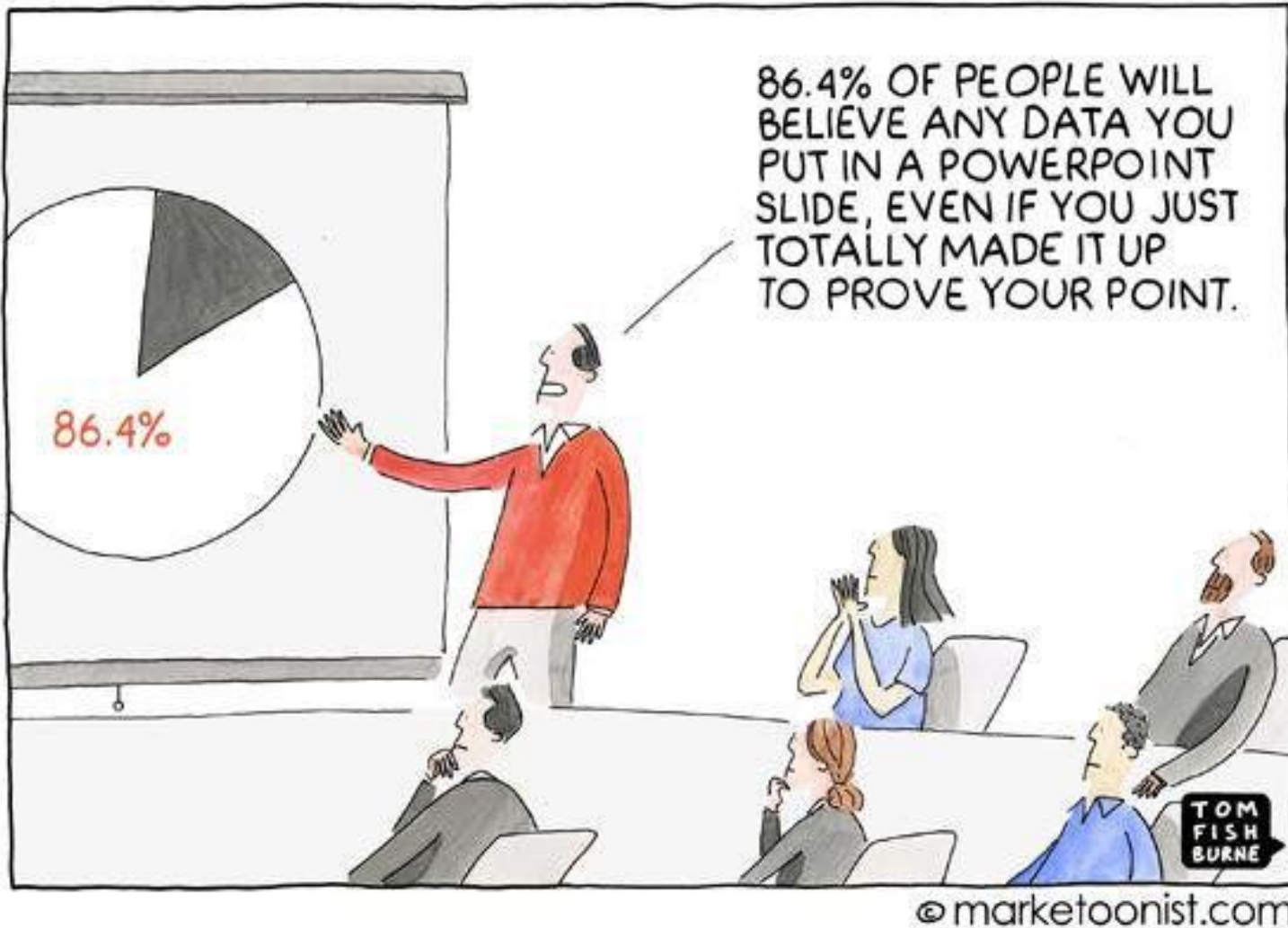
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Evidence-based advocacy – What is it?

Systematic and targeted collection, interpretation, generation and deployment of sound data and information, presented and used in **patient advocacy with an objective in mind.**

Advocating in a targeted, evidence-based, well-educated and professional manner, and measure impact and outcomes of what we do.





Why use
evidence?

Credibility



Why use
evidence?

Understanding

Responsibility on the patient community to use EBA to drive change...

UK based patient experience survey of 2,329 leukaemia patients from Leukaemia Care.

Used to identify unmet needs and to inform:

- Organisational strategy
- Campaigns – e.g. patient issues
- Evidenced access arguments – to inform NICE submissions
- Publish at scientific conferences

Leukaemia Care
YOUR Blood Cancer Charity

Leukaemia Care Living with Leukaemia

2018 Report



www.leukaemiacare.org.uk

How to use evidence..

1. Listen to the evidence
2. Act on the evidence

DO NOT use evidence just to back up your existing point of view



I see here that I'm right about everything.

MOMENTS OF TRUTH

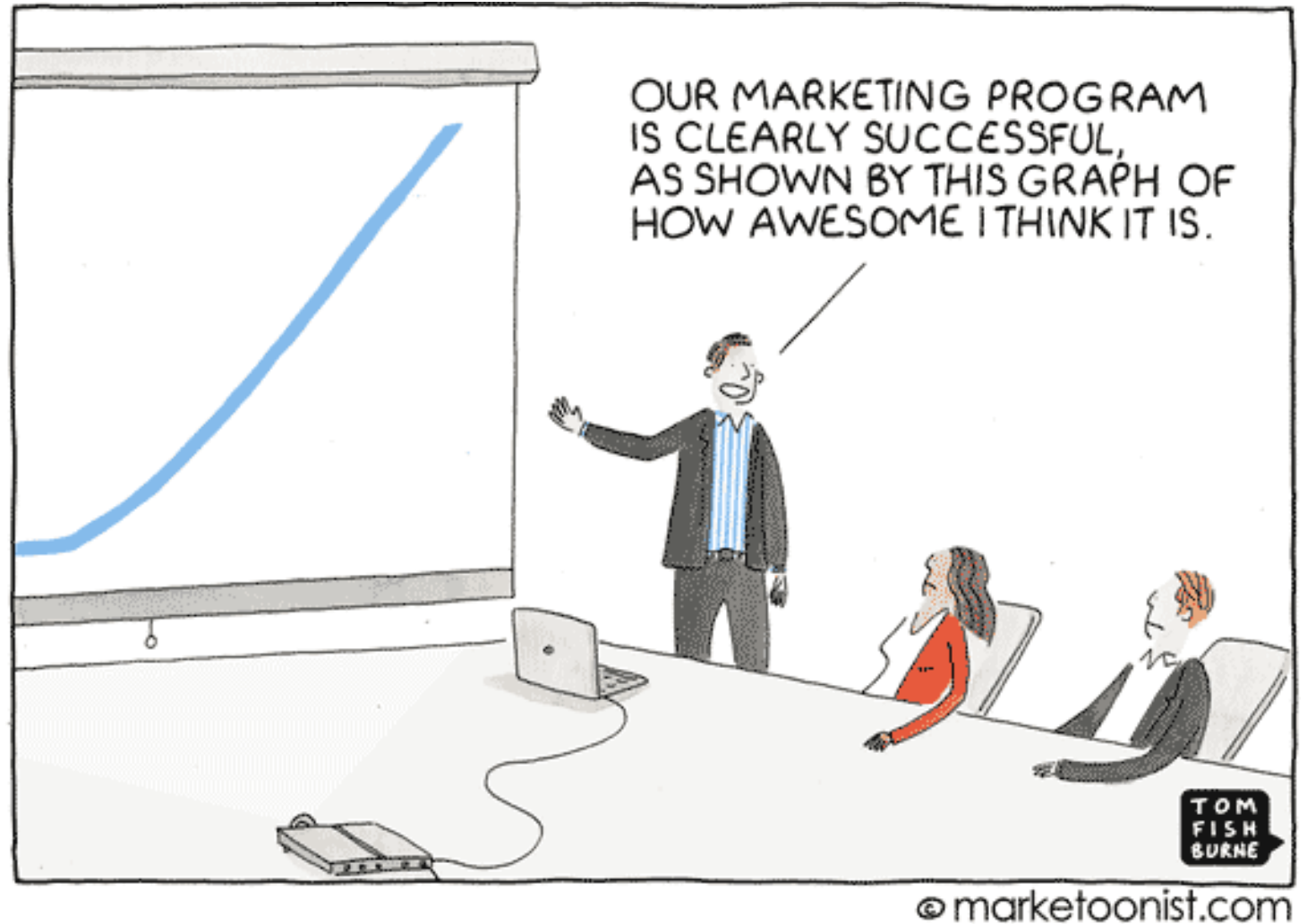
by Tom Fishburne



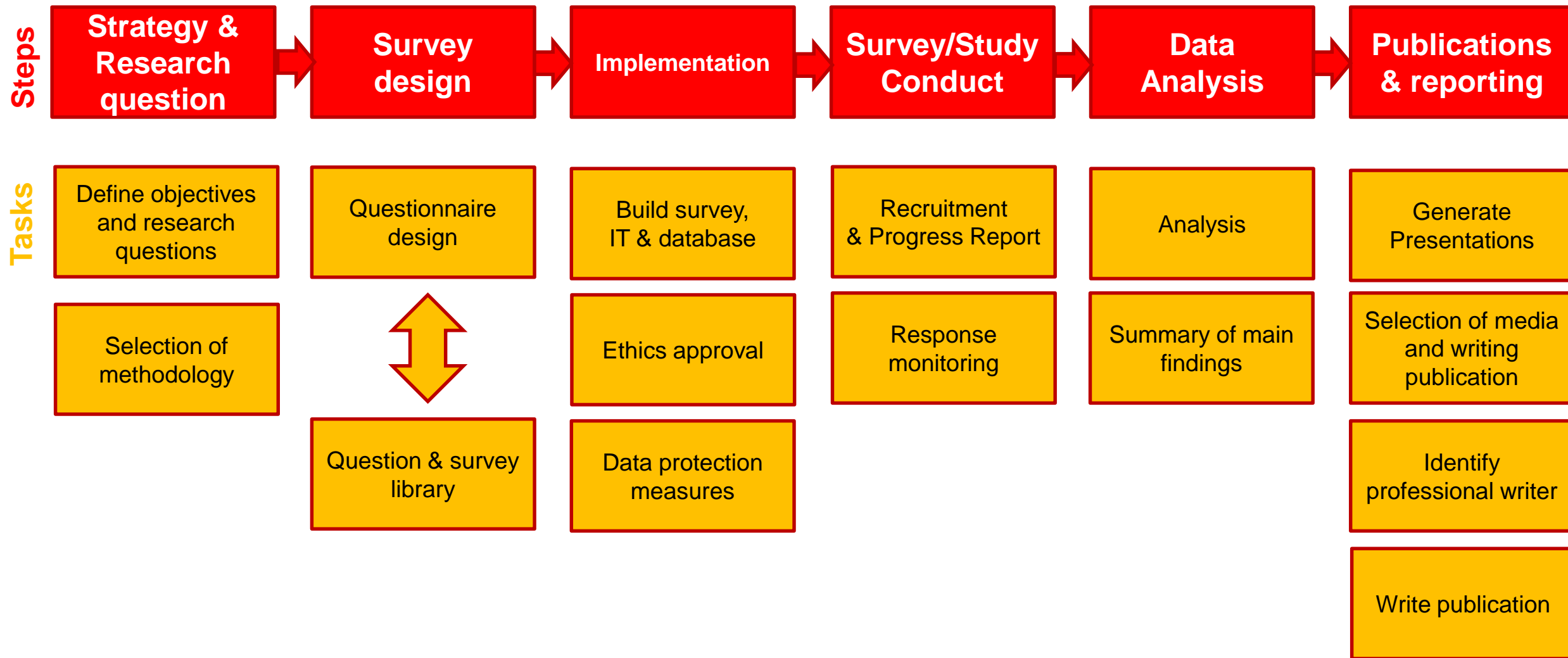
Methodology
is key...

Does your evidence show what you think it does?

- Did you ask the right question?
- Did you ask the right people?
- Did you ask enough people?
- Is your conclusion what the data shows?
- Is it statistically valid?



Key elements of evidence generation for EBA



Be clear from the start how you want to use the data

YOUR PURPOSE DETERMINES WHAT TYPE OF PROJECT TO RUN...

Setting your strategy and research question?

At the **outset** of any project, and at any point you make significant **changes** to your plans, ask yourself:

- What am I trying to achieve?
 - What is your desired advocacy impact?
 - What do you want to show, and to whom?
 - What evidence do you need to back up your work?
 - What is already known and what do you need to collect?
 - What types of evidence will be most effective with your stakeholder group?
 - What is your analysis strategy?
- Everything flows back from this – e.g. type of evidence generation, publication decision – consider undertaking strategic review

Steps

**Strategy &
Research
question**

Tasks

Define objectives
and research
questions

Selection of
methodology

What is already **known**?

As a general rule of thumb...

Use to help identify:

1. What **type** of evidence **generation**
 2. **What** to collect evidence on?
 3. Or whether you even need to collect any?
- Thinking here about what is known to **other researchers**
 - And what is **only known** to patients and/or advocates

	Known (YOU)	Not Known (YOU)
Known (OTHERS)	EXISTING EVIDENCE	DESK RESEARCH
Not Known (Others)	QUANTITATIVE	QUALITATIVE

Considering type of evidence generation (e.g. survey)

Depending upon your aims there are different (and complementary) approaches:

- Pure Questionnaire – e.g. multiple choice, rank order or ‘tick box’ Qs
- Pure Interview – written/oral structured open Qs
- Mixture – e.g. some multiple choice and some open Qs

In terms of designing questions:

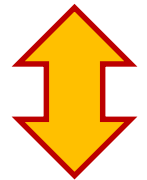
- Create your own – e.g. in a novel area
- Use existing questions
 - Entire PROMs - within a questionnaire
 - Individual Qs – from question and survey library

Steps

**Survey
design**

Tasks

Questionnaire
design



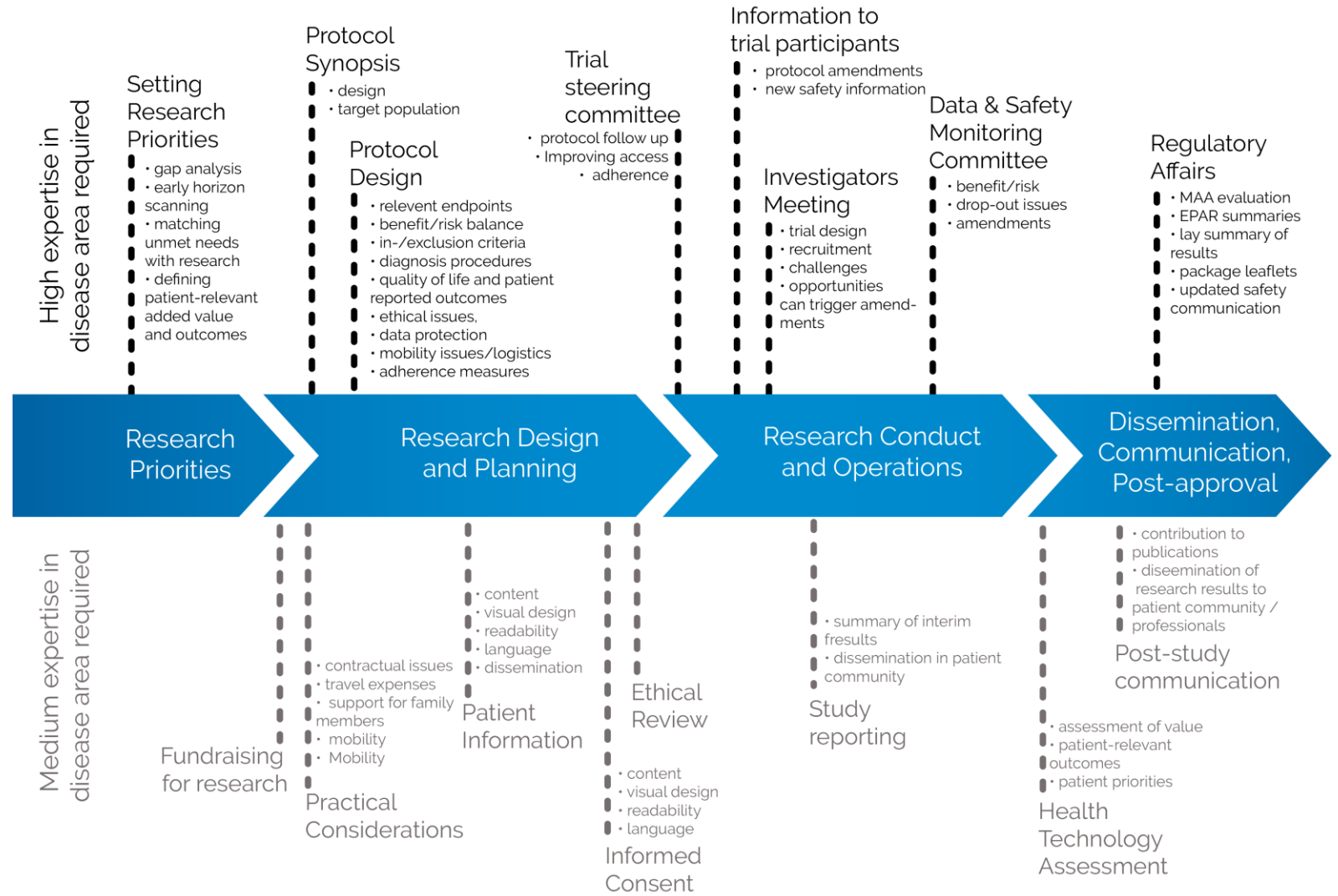
Question & survey
library

Don't just generate evidence for the sake of it!

BE CLEAR AT THE START ABOUT WHAT DATA YOU NEED AND HOW IT
WILL BE USED

Patients should also be involved in external evidence generation...

Patient involvement in medicines R&D



Case Study: Living with leukaemia

LEUKAEMIA CARE

Project Overview



Aims – Exploring UK leukaemia patient experience



Topics – Following the journey from diagnosis onwards



Testing – To refine the content



Comparability – between annual versions



Patient Survey

This questionnaire is about your care and treatment for a blood cancer. Its purpose is to provide information, which can help the NHS and Leukaemia CARE monitor and improve the quality of health services for future patients with blood cancer.

Taking part in this survey is voluntary. Published reports will not contain any personal details.

Who should complete the questionnaire?

The questions should be answered by you, as the person who has been treated for a blood cancer. If you need help to complete the questionnaire, the answers should be given from your point of view – not the point of view of the person who is helping.

Completing the questionnaire

For each question please tick clearly inside the box that is closest to your views using a black or blue pen. Don't worry if you make a mistake; simply cross out the mistake and put a tick in the correct box.

IMPORTANT INFORMATION

To make sure the information we collate is useful, we need to collect some personal details from you and access information held about you in other NHS databases. The purpose of collecting this information is to generate aggregated statistics about the care and treatment people receive. These statistics will be used to compare the differences in care and treatment by different providers and to understand what may be causing these. The results will be used to measure and improve the quality of healthcare services.

By completing this questionnaire you are giving your consent for the information provided to be used for the above purposes. Specifically, you are agreeing that:

- Your personal details and relevant health information can be held and used by an organisation contracted to Leukaemia CARE to analyse the data.
- Your personal information will be handled securely and anonymised after analysis and before any publication.
- Your personal information will not be released by anyone working on behalf of Leukaemia CARE unless required by law or where there is a clear overriding public interest.
- You can withdraw the information you give Leukaemia CARE in this questionnaire upon request, up to the point at which data are analysed and personal details removed.

If you have any queries about the questionnaire, please call the FREEPHONE helpline number on 0800 783 1775

LE17CORE

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Methodology: Cohorts

CPES

- Patients identified using the NHS CPES survey

Leukaemia Care

- LC Database
- Had a valid postal address (for paper survey)

Anonymous

- Online link
- Wider blood cancer community
- LC email consent

Different output types

Reports and Presentations

Scientific Publications

As a starter for follow-up projects...

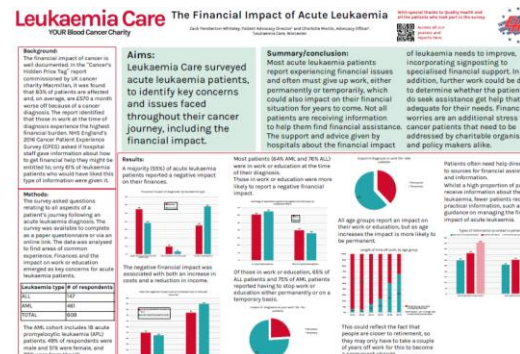
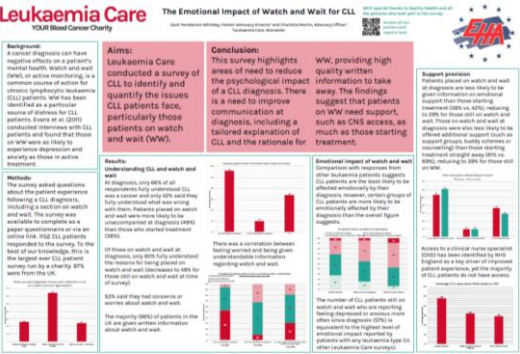
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Leukaemia Care Living with Leukaemia

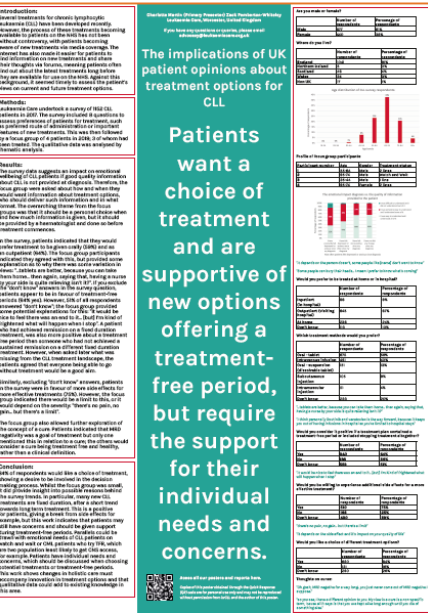
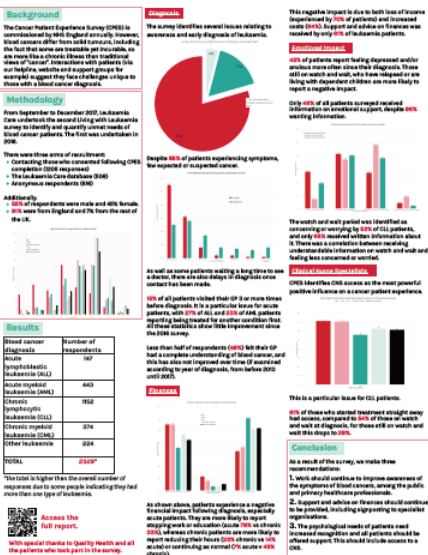
YOUR Blood Cancer Charity

Background: The Cancer Patient Experience Survey (CPEX) is commissioned by NHS England annually. However, most cancer sites have not yet started, including the first test sites and therefore no results, or "Year 1" results, have been published. Leukaemia Care is a patient-led charity and therefore has a unique perspective on the patient experience. We have conducted a survey of patients living with leukaemia, to identify and quantify current needs of blood cancer patients. The first was undertaken in 2018.

Methodology: From September to December 2017, Leukaemia Care conducted a survey of living with leukaemia survey to identify and quantify current needs of blood cancer patients. The first was undertaken in 2018.

Results: The survey identified several issues relating to the experience of living with leukaemia. The most common issues were related to the impact of the disease on daily life, the need for support, and the need for information. The survey also identified a need for support and information for patients on watch and wait.

Conclusion: The survey identified several issues relating to the experience of living with leukaemia. The most common issues were related to the impact of the disease on daily life, the need for support, and the need for information. The survey also identified a need for support and information for patients on watch and wait.



+ Journal articles

Leukaemia Care
YOUR Blood Cancer Charity

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www.leukaemiacare.org.uk

NICE
National Institute for
Health and Care Excellence



How can patient groups use RWE in their activities?

EXAMPLE FROM LEUKAEMIA CARE (UK)

**Leukaemia Care
Living with Leukaemia**

2018 Report



www.leukaemiacare.org.uk

Defining Unmet Needs

Identify: What are the issues to focus on

Measure

- Quantify issues (e.g. the % of patients experiencing)
- Differences between particular groups. such as demographics, cancer type, regions, time

Solutions: Create a set of recommendations to address

Further Questions - Is there anything you need more evidence on?

Strategic plan for Leukaemia Care 3 years – 2019 to 2022

Presented to the Trustee Board
23 January 2019



Organisational Strategy

How are you going to address the unmet needs?

Questions to think about:

What are you already addressing?

What should you do differently?

What do you need to do more of?

What are you not doing?

What can you **NOT** do? What should be worked on by others?

Collect Further Evidence

Use Key Performance Indicators (KPIs) – to measure outcomes and impact

Collect data and compare – e.g. performance across years

Developing New Services

One you have identified an unmet need to focus on...

- Designing the service – what exactly do you need to address?
- Use evidence for your funding application
- Use feedback to refine existing services
 - Use Key Performance Indicators (KPIs) – to measure outcomes and impact
 - Individual feedback from users (e.g. survey)
- Consider running a small PILOT to show it works?



Campaigns – Awareness and Early Diagnosis

Understand your audience

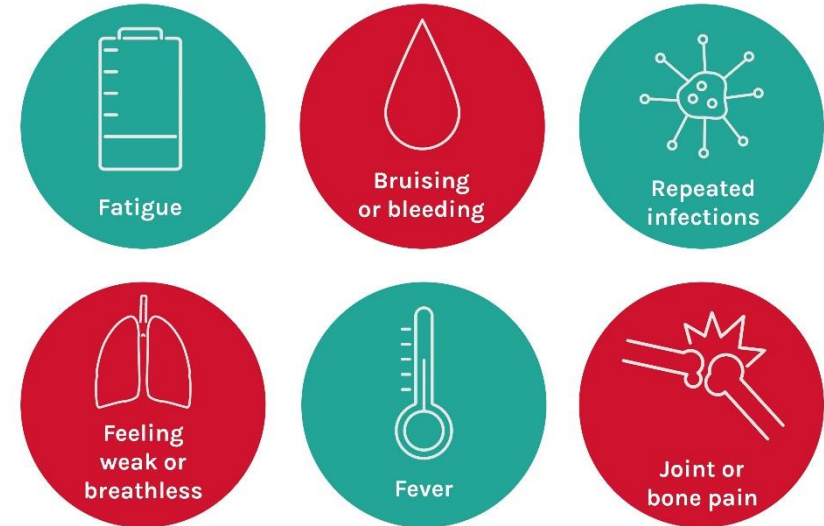
- Public v Patient – are you targeting a specific demographic?
- What does the audience already know?

Use Evidence

- Your own (e.g. survey)
- External (e.g. NCIN Routes to Diagnosis)

Consider your message

- What does the audience need to know?
- Where to focus? – e.g. MPN, blood cancer or cancer





Campaigns – Patient Issues

- Using evidence to develop and run campaigns to address specific issues
- **Audience** – Patients? Clinical community?
- **Evidence** – Tailor to look at differences? Can you do a specific survey? Or breakdown of an existing survey?
- **Message** – What are you trying to change?

Example: ‘Watch Wait Worry’ campaign

- We developed:
 - Evidence Report – for clinicians
 - Supportive guidance for CLL patients on watch and wait
 - Social media campaign
- Poster at EHA on the emotional impact of watch and wait for CLL

Access: Health Technology Appraisals

- Different HTA processes have different opportunities for patient organisations to get involved
- In most cases the consideration of patient perspective is **qualitative**, so it is difficult to understand the impact on decision making
- You can create **quantitative** evidence (e.g. patient surveys), but at present there is no mechanism for the inclusion of such evidence
- Focus on:
 - Influencing the areas that influence decision making (e.g. cost-effectiveness)
 - Impact not involvement
 - Explaining existing evidence (e.g. trial) and the benefit from a patient perspective

NICE
National Institute for
Health and Care Excellence

